Evidence of Nonverbal Self-reported Quality of Life in Medically Complex Children

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Statement of the Problem

• Quality of Life (QOL) assessment is a fundamental aspect of understanding patients/families’ needs when confronting a serious or life-threatening condition.
• Does the literature offer evidence for QOL assessment and do practicing pediatric nurses have the knowledge and skills to assess QOL in nonverbal medically complex children?

Background/Literature Review

• Current evidence suggests reliance on parent or caregiver-proxy and a lack of consensus on best practice guidelines and QOL assessment tools.

Barriers/Limitations

Existing literature and nurse respondents identified barriers and limitations in appropriately assessing QOL from the child’s own experience:
• lack of clinical documentation
• lack of validated pediatric QOL assessment tools
• lack of nursing education
• discomfort communicating with nonverbal children

Nurses Primary Practice Location

• Homecare Agency
• Outpatient Center/Ambulatory Care
• Inpatient Hospital
• Home Palliative Care/Hospice

Nursing Experience

Mean: 9 years
Most: 36 years
Least: 1 year

Methods

• Search for evidence reviewed literature, guidelines, policies, and quality improvement projects related to medically complex children
• A nursing needs assessment was developed to serve as a primary source of evidence and was completed by 45 pediatric nurses in Spring 2019

Implications

Additional education and development of appropriate QOL instruments are needed to assist healthcare professionals and families in understanding children’s own needs when words are not available.

Dissemination

Translating Research Into Practice (TRIP)
Nonverbal Self-reported Quality of Life in Medically Complex Children

What Does the Evidence Say?
Quality of life (QOL) is a term used when patients, families, and healthcare professionals agree on the quality of a specific condition. There are two main dimensions: physical aspect and emotional aspect, and it can only be determined by the person who is experiencing the condition.

Evidence of Nonverbal Self-reported Quality of Life in Medically Complex Children

Purpose
• Current evidence suggests reliance on parent or caregiver-proxy and a lack of consensus on best practice guidelines and QOL assessment tools.
• Most (80%) pediatric nurses stated it is extremely important to assess QOL in children unable to speak.
• Consistent with literature, pediatric nurses rely on parent report, physical condition assessment, displaying expressions/emotions, or provider assessment of QOL.
• Although nurses (89%) reported they have NOT received formal education on how to assess QOL, almost half (44%) are asked to assess QOL at least once a week.

Findings

• Most (80%) pediatric nurses stated it is extremely important to assess QOL in children unable to speak.
• Consistent with literature, pediatric nurses rely on parent report, physical condition assessment, displaying expressions/emotions, or provider assessment of QOL.
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Barriers/Limitations

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Acknowledgements/References

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References:


**What Does the Evidence Say?**

“Quality of Life (QOL)” is a term used when patients, families, and healthcare professionals are trying to understand the impact of serious illness. There are two key concepts associated with QOL: 1) It is multi-dimensional and includes physical, social, psychological, and spiritual dimensions, and 2) it can only be determined by the person (https://getpalliativecare.org/quality-of-life).

Although family members, nurses, physicians, and other health professionals can make significant observations, research consistently shows important differences between how patients, and those around them, interpret the question: How is your quality of life? In children who cannot self-report it is difficult to understand QOL dimensions from their own perspective (Lim, Velozo, & Bendixen, 2014)(Jones & Weisenfluh, 2003).

There is still a lack of consensus on best practice guidelines and QOL assessment tools. Current recommendations remain relying on parent or caregiver report in response to questions in an individualized care plan or goals of care conversation (Marino et al., 2011; Hinds, Menard, & Jacobs, 2012).

**Pediatric in Practice?**

Pediatric nurses have information available to them, beyond parent report, to assess a nonverbal child’s QOL:

1. Assess physical condition (e.g., pain, functional status, and unrelieved symptoms) (Cheng et al., 2018)
2. Coordination of care with Expressive Therapists (e.g., Play Therapy, Creative and Expressive Arts Therapy, Movement/Dance, PT, OT, Speech, or Massage) (Ekberg, Bradford, Herbert, Danby, & Yates, 2015)
3. Communication directly with the child using and adaptive/augmentative communication device (Markham, Van Laar, & Dean, 2011; Montgomery, Sawin, & Hendricks-Ferguson, 2017)
4. Assessment of emotions (displaying expressions of fear/anxiety, lack of control, etc.) (Menteer, Beas, Chang, Reed, & Gold, 2013)
5. Intake of sociocultural stressors (distress about siblings/parents, isolation, socioeconomic effects on well-being, specific cultural/ethnic practices of the family)

**Validated Assessment Tools**

1. The PedsQL™ (Pediatric Quality of Life Inventory™), with specialty pediatric assessments for:
   - Gastroenterology
   - Cardiology
   - Oncology
   - Neurology
   - To Access Visit: https://www.pedsql.org/

2. KIDSCREEN Questionnaire
   - To Access Visit: https://www.kidscreen.org

**References:**


